



Little Giants • Great Letters

Little Giants • Great Letters

How are you? I'm one of the Little Giants.

My handwriting is a bit messy because a tiny pencil is already too heavy to me.

I'm as tall as a kid but inside I'm an adult.

I cannot walk freely but I can see the discrimination against me.

I'm a rare patient. I might not live more than 20 years if I don't receive medication.

My family has been protecting me. I think I feel more love than normal people do.

And, I'm no longer lonely.

There are patients with rare genetic diseases like me in Hong Kong. We're supporting and encouraging one another. And we walk together.

Some kind people in Hong Kong understood us and gave us support.

We're trying to let more people know about the disease and our condition, and tell the government that every life is precious.

Like a normal person, I have lots of dreams.

Thank you for flipping through this book. Please continue reading about my dreams patiently.

See you later!

Love,
Little Giant
July 2008
Hong Kong

你好嗎？我是醃豆豆。

我寫的字都是東歪西倒的，因為小小的一根鉛筆，對我來說，有千斤重。

我像個孩子般矮小，可是思想早已長大成人。我不能夠隨意走動，可是身邊的歧視我都一清二楚。

我是很罕有的病人，如果得不到適當治療，我活不過20歲。

家人一直守護我。我想，我獲得的愛遠比平常人多。

漸漸，我不再孤獨。
香港有着一小群像我一樣的罕有遺傳病患者。
我們互相支持、鼓勵。

然後，我們不再獨行。
香港有着一小群體會我們處境的有心人。
我們一起設法，讓更多人體會我們的處境，
也不斷向政府說：「每一條生命，都是珍貴的。」

和平常人一樣，我的夢想很多很多。

謝謝您翻閱這本書，請繼續用心閱讀我的夢想。

待會兒見！

醃豆豆上
08年7月
香港

If Your Life Were a Letter

What is Mucopolysaccharidoses (MPS)?

Tang Wai-man X Amanda Fung
Danny Tang X Yanki Lee

Mavish Sultana X Anothermountainman
Hamza

Chau Hiu-yin X Clement Yick
Jay Shum

Eric Ma X Ducky Tse Chi Tak
John Lee

Mak Chi-yan X Gideon Lai
Lee Sum-yu

Annie Yeung X Shana Cheung
Johnny Yeung

Doctor's Words: Treatment Trends in MPS

Acknowledgements

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www.mps.org.hk

A Bbluesky caring project



If Your **Life** Were a Letter

Famous painter Vincent van Gogh once said, "An artist needn't be a clergyman or a churchwarden, but he certainly must have a warm heart for his fellow men." Indeed, what makes a great artist is not wealth or knowledge, but a heart that loves life.

Only people who cherish life can live one full of hope. They can transform dreams into art, and warm the frosty world.

"**Little Giants**" are MPS patients, like my own son. They were born without a particular enzyme, thus doomed to a short life. MPS is not untreatable; we just cannot afford the medical bill of nearly a million dollars every year.

The most pitiful part is that the disorder is so rare that the government and people in society often overlook the straits patients are in. In the end, seeing our beloved ones getting weaker day by day is all we could do.

"Little Giants" have a small body, yet big dreams. They love their families, respect their teachers and cherish their lives. In fact, they are all life's artists because they know how to love a bitter life better than normal people.

"**The Big Ds**" are 7 outstanding designers and creators in Hong Kong. By corresponding with 12 patients, they learnt about the Little Giants' dreams and feelings in their heartfelt conversations.

The interactive creative project "**Little Giants X the Big Ds**" comprises the correspondence and artworks of Little Giant and the Big Ds, the exhibition "**Little Giants X the Big D's**" Artwork Exhibition held at Taikoo Place in May, and the publication of this book, "Little Giant · Great Letters". Through letters and face-to-face conversations, the designers sought to understand the inner world of the patients and manifest their dreams on the exhibits. The patients did not see any of the exhibits until the exhibition. And they were all amazed. They found that their dreams could be expressed through something as simple as a normal cardboard box, fill-in-the-blank questions, cushions, badges, pot plants, watercolours and transparent plastic boxes. These items utterly laid their thoughts bare.

This book, "Little Giants · Great Letters", is published to announce the patients' will to the world. Hopefully more people would understand that a weak body does not necessarily obstruct one's firm approach to dream. Apart from letting the public learn about us, the exhibition was a mirror to let the patients view themselves in diversified perspectives. Despite the illness, it is their choice to live happily. One of the artworks displayed a simple English word "NOWHERE". To most of us, it appeared as "NO WHERE"—meaning "No Exit". But it was in fact "NOW HERE"—The exit is right here.

I have to thank the "Big Ds" for their enthusiastic support. The 7 designers were Amanda Fung, Anothermountainman (Stanley Wong), Gideon Lai, Clement Yick, Ducky Tse, Shana Cheung and Yanki Lee. I would also take this opportunity to thank Bbluesky for planning the event and publication, and all the people and organisations who have supported us in different ways, including The Hong Kong Society for Rehabilitation Community Rehabilitation Network, Genzyme Asia Limited, GlaxoSmithKline, Taikoo Place and Bio Marin Pharmaceutical Inc., which sponsored the exhibition.

Unfortunately, we are still the minority. Our request is yet to be addressed.

Despite our pleading for a full sponsorship for medication, the government has been turning us down. We can only face our predicament and carry on with our lives. We hope that the public would know more about the suffering MPS patients, and treasure the right to live like we do.

If your life were a letter, I wish that it were like the Little Giants'—full of love and passion.

If you hope that the Little Giants' letters and lives would receive a response, please write back after reading this book.

Stephen Ma
Chairperson
Hong Kong MPS & Rare Genetic Diseases Mutual Aid Group
June 2008



What is MPS?

Mucopolysaccharidoses (MPS) is a congenital metabolic disorder, which is a kind of lysosomal storage disorders. Mucopolysaccharides is a chemical that comprises molecules similar to sugar. It is the main component of human tissues and organs. The cause of MPS is the lack of a particular enzyme to break down mucopolysaccharides in the body. Accumulation of mucopolysaccharides in the human body can damage different organs, causing dysfunction.

Common Symptoms

The lack of the specific enzyme varies from person to person. MPS is therefore divided into 7 types (Type I to Type VII). An MPS patient may show no difference from a normal person at birth. However, various symptoms would gradually become visible as mucopolysaccharides accumulate. Common symptoms include: short body trunk, bulging forehead, thick brows, excessive facial and body hair growth, flat nose bridge, thick lips, stiff joints, short and claw-like hands, enlarged liver and spleen, protruding abdomen, umbilical hernia, cloudy cornea, etc.

Different types of MPS cause damages to different organs. Some are mild, but some severe. In terms of brain function and intelligence, MPS I, II and III patients might have severe intellectual disability, while IV and VI patients are just like normal people. MPS IV mainly affects the patient's skeleton.

Treatment

In early stages, bone marrow transplant can help regress MPS I and VI patients' symptoms so they can live longer. Apart from that, there are now enzymes to treat MPS I, II and VI. Enzyme injection, however, cannot help with the patient's brain function and intelligence because those enzymes cannot directly get into the brain. The injection must be regular and ongoing or it will be useless.

Nowadays, there are about 30 to 40 MPS patients in Hong Kong. Rare inherited disorders are often called "Orphan Disease" as the number of patients is so small. Patients are easily ignored by the government, and therefore cannot get sponsorship or support. Even though there are medicines available, they are extremely expensive and unaffordable for ordinary families, as if it is a "visible but unreachable dream".

Hong Kong Mucopolysaccharidoses & Rare Genetic Diseases Mutual Aid Group

Our group is formed by patients with MPS and other rare genetic diseases and their family members. We aim to support and encourage patients and families suffering from these diseases. With the assistance of Hong Kong Society for Rehabilitation Community Rehabilitation Network, our group officially became a charity on 23 March 2005. We published the book "Little Giants – Dreams of Braving MPS" in September 2006 to let the public know about MPS patients and their dreams.

Apart from MPS, some of our members are patients with Mucopolipidosis, Glycogen storage disease, Multiple Sclerosis, Gaucher's disease, Pompe disease, Hereditary epidermolysis bullosa, Phenylketouria, Glutaric aciduria Type I and Sotos Syndrome. We welcome patients with other rare genetic diseases to join us. If you would like to know more about these rare genetic diseases, please visit our website at www.mps.org.hk



We Are the **LITTLE GIANTS**



Tang Wai-man (right)—Danny Tang’s older brother

- 44-year-old
- Patient with mild MPS II
- Oldest MPS patient in Hong Kong, according to existing medication records
- Eldest son in family
- Quiet person who enjoys thinking
- Devotee of sustainable living and healthy eating
- Dream: Live healthily and receive treatment just like the other adult patients in other countries

Danny Tang (left) – Tang Wai-man’s younger brother

- 41-year-old
- Patient with mild MPS II
- Lively person who enjoys a colourful life
- Former logistics worker and kitchen assistant; a casual worker now
- Dream: No discrimination



We Are the “**Big Ds**”



Amanda Fung graduated from BA(Hons) in Environment and Interior Design, PolyU Design, in 1996. She had worked for several renowned interior design firms and construction consultants. In 2005, she set up FAD Interiors, which focuses on stores, show flats and clubhouse projects. She won the Honourable Award (Shopping Space) in 2007 Asia Pacific Interior Design Awards (APIDA).

Yanki Lee graduated from the School of Architecture, Royal College of Art (RCA), London, in 2000. She has experience in studying and researching international architecture design in both London and Hong Kong. In 2007, she was awarded a Ph.D in Design with her thesis “Design Participation Tactics: Involving people in the design of their built environment”. Yanki is now working at RCA Helen Hamlyn Centre on research programmes, focusing on design participation, the social meaning of design and community architecture.



Little Giants' Great Letters



The mucopolysaccharides in my body have changed a lot since the beginning. My organs and sensory system are affected to different degrees as mucopolysaccharides accumulate. My face ages quicker than others. I could only strengthen my body to slow down the deterioration. With my limited life, I could only make myself a more insightful and thoughtful person.

Tang Wai-man
MPS II Patient

In European and American countries, or our neighbours Taiwan and Japan, adult MPS patients can receive the Enzyme Replacement Therapy with full sponsorship from the government. In Hong Kong, however, we are not protected by the government's healthcare policies. The condition of our bodies and organs is getting worse day after day. In a world like this, is "waiting" all we could do...?

Danny Tang

Big Ds' Replies

Dear Wai-man,

I'm really happy to have known you and your brother.

To be frank, I didn't know much about MPS before I met you. I had read about it in newspapers and magazines, but I had never encountered an MPS patient. Your letters and our conversations have deepened my understanding of the disease. I'm pleased that you're passionately working, contributing to society, making friends and developing diverse interests despite the inconvenience brought by the disease. You have earned my respect.

It surely takes effort to stay healthy—exercise more, rest regularly and have a balanced diet. I'm deeply impressed by your knowledge of healthy eating. You're like an encyclopedia of health. I've learned a lot from you. I'm ashamed that I didn't care much about my health but my work.

Your positive attitude for life has inspired me to create the exhibit "Happy Planter".

Planting is an art, which requires effort and patience. Seeds have remarkable vitality. Once they've gained a sufficient supply of water and nutrients, they sprout and grow strong. No matter where the plant is, its leaves will grow toward the sunlight. And very soon, the plant blossoms and bears fruit. I'm sure that with your effort to strengthen your health and mind, you can live a colourful life just like the tiny seeds.

Much love,
Amanda

Dear Danny,

Hello! It was a pleasure meeting you, your brother and your mother. I'm now back in London.

Like many others who do not know about MPS, I made a lot of assumptions before I met you: Have you been living in pain? How was your life like in the past 40 years? Is it full of sorrow and sympathy?

But when we started talking to each other, I noticed you were wearing a pair of chic "New Balance" black and gold sneakers. They reminded me of the time when I hung out with some disabled friends in the UK. They were independent and willing to share their of views on aesthetics. And there was no discrimination.

"What are you looking at?" you said when people quizzically stared at you. You told me you were tired of explaining your condition for so many times. I came up with in idea—to develop a brand called MPS2. I got the inspiration when I saw your brother's letter. He wrote "MPS2" below his name as if it is part of his identity. I'd like to develop the brand MPS2 and a set of products for you (The acronym "MPS" and 7 numbers are printed on a black round stamp, representing the 7 types of MPS). We would display photos of you wearing the products and invite you to be an MPS2 ambassador to let the public know about the disease.

Thank you for your participation. This has been such a valuable and inspiring experience for me.

Warmly,
Yanki



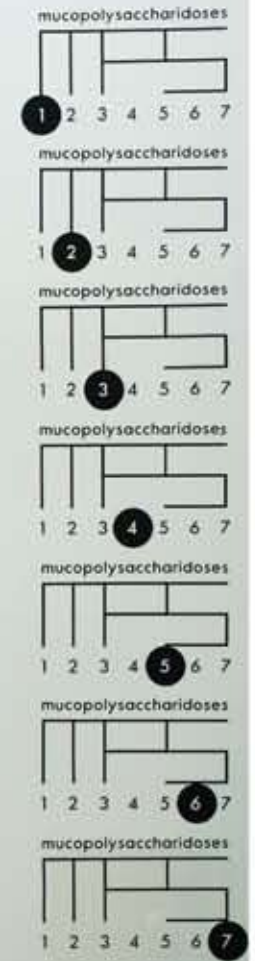
Tang Wai-man × **Amanda Fung**

Little Giant × **the Big Ds** Exhibit

“Happy Planter” consists of stacked pots of various sizes and shapes. You can grow different types of plants as you prefer. You only have to water the top. The water will then trickle down to the next layer and so on. It is not only a functional planting pot, but also an artistic home decoration. Hopefully, this exhibit can spark your interest in growing potted plants, and add a sprinkle of fun to daily life. We wish your life could flourish like a flower.



Danny Tang, over 40 MPS2 ambassador



Danny Tang × Yanki Lee

Little Giant × the Big Ds Exhibit

The inspiration of setting up the brand MPS2 came from Tang Wai-man's letter, in which he wrote "MPS2" below his signature as if it was part of his identity. The acronym "MPS" and 7 numbers are printed inside a black circle, representing the 7 types of MPS. Having Danny as an MPS2 ambassador with the themed shirt, we hope to increase people's understanding of the disease.



We Are the LITTLE GIANTS

Mavish Sultana (left)—Hamza’s older sister

- 13-year-old
- MPS I patient
- Pakistani born in Hong Kong
- Raised by mother after father’s departure
- Lively person who loves beauty
- Dreams: 1. Be able to afford treatment; 2. Return to Pakistan soon because no one in Hong Kong does impish tricks and chats with her; 3. Be a pretty and smart girl; 4. Become a doctor to help patients

Hamza (right) – Mavish’s younger brother

- 11-year-old
- MPS I patient
- Pakistani born in Hong Kong
- Raised by mother after father’s departure; Loves his mother and sister
- Quieter person compared to his sister
- Dream: Get stronger when he grows up so that he could take care of his mother and sister



I’m the “Big D”



Another mountainman (Stanley) was born in Hong Kong in 1960. He graduated from Hong Kong Technical Teachers’ College (Design & Technology). After 5 years working as a graphic designer, he began his career in the advertising industry. He had worked for a number of advertising companies.

In 1996, Stanley relocated to Singapore and became the Asia Creative Director of Bartle

Bogle Hegarty, a British advertising agency. He was the first Chinese to take the position.

He returned to Hong Kong in 1999 to become the CEO and Executive Creative Director of TBWA Hong Kong.

In 2000, he joined Centro Digital as Chief Creative Officer and Film Director.

In July 2002, he established Threetwoone Film Production Limited. In 2004, he was inducted into the Alliance Graphique Internationale (AGI).

With all his passion for creation, he set up 84000 Communications in 2008 to engage in various design projects.

Stanley’s designs, photographic works and advertisements won more than 400 local, continental and international awards over the past decade or so. Regarding design education as an important part in the rest of his career, he has been busy visiting local and overseas institutions in recent years. Apart from designs and advertisement, Stanley is devoted to photography and art. He focuses on themes related to human rights and social circumstances.

In the past few years, his Red White Blue series came to fame in Hong Kong and all around the world. The series represented Hong Kong in the 2005 Venice Biennale.

Little Giants' Great Letters



My name is Mavish Sultana. I am 13 years old.
I am suffering from MPS type 1.
I am a girl and I wish to have everything others have like their height, most of the girls my age are taller than me and faster than me. I wish that I will get the medicine as soon as possible so that I can tell everybody that I am not different from them and I also want to be a doctor when I grow up to help people who are ill...



My name is Hamza,
I am 11 years old.
I am suffering from MPS disease type 1.
I feel sad about my condition because I am different from others.
I wish that I will get the medicine as soon as possible so I may feel much better.
My mother is a housewife. She cannot afford the medicine but we know that she really wants to help us and I want to take up the responsibility of my family when I grow up.



Big D's Replies

Dear hamza and mavish,

How are you today?

Last sunday, I went to a very beautiful garden with my wife and friends. It is in diamond hill near the old airport, not far away from where you live. It is not very big. It is built based on the architectural style of the chinese tang dynasty: golden little house, orange colour footbridge, a lot of hundreds year old pine trees and stones with different patterns mined from under the china sea. Birds were singing and the sky was very blue that day...

It was a beautiful day for me. Peaceful, sweet air under the trees instead of a busy shopping day in causeway bay.

Life is beautiful, it all depends on how you see it and how you chose them...

What are the most beautiful thing(s) you treasure most?
And what do you like in this world?

Talk to you very soon.

Uncle stanley
(By the way, how are things going with your drawing book?
A lot to show me now? Hamza, pls forward this email to Mavish.)

Hi uncle Stanley,

Life is beautiful.

You want to know how?
Last month I went to Sai Kung country park. The sky was blue and the wind was blowing so hard that I felt like I was going to be blown away too.

I have lots of dreams, to be normal like other kids. My height is the same as a five year old kid. I wish to be tall like my friends but I am still happy for one thing, that I have a normal mind. Same for Hamza. He also thinks in this way.

Mavish

Little Giant's Reply

Mavish Sultana

Anothermountainman

Hamza

Little Giant

the Big Ds

Exhibit

seeing/believing

One evening, I was sitting on a sofa at Marvish and Hamza’s home at Sau Mau Ping. They were cute and innocent, smiling as if the disease didn’t bother them.

This was the first time I met them.

Hamza’s dream is to become a scientist to protect his mother and sister.
Marvish is determined to become a doctor to help the patients in need.

I gave them a drawing book. Inside the front cover was the quote, “people always say, seeing is believing”.
Uncle Stanley, “I believe... then I will see...”
I didn’t expect excellent drawing from them, I only wanted to use the line to start our interaction and sharing.

I was touched by their positivity.
I could see they knew what they wanted, they believed in themselves,
that one day they could help others.

Being right beside them, do we believe in hope in the first place?
To believe that medication could bring them a better life.
To believe that life could be continued.
Even to believe that there are visible miracles.





Little Giant the Big Ds Exhibit

nowhere/now here

Walking on a road,
It could be a 140-km-high rack
It could be endlessly straight
It could be rough and winding
It could be...

As long as it's going forward
Don't you ask about your pace
Don't you ask about your
destination
The Absolute is not absolute
But the Relative.

Don't you surrender
When you see nowhere
Nowhere...
It could be a start
Now Here...



We Are the **LITTLE GIANTS**

Chau Hiu-yin

- 15-year-old
- MPS IV patient
- Had surgeries in the neck, thigh and pelvis before the age of 4; Afraid of blood taking.
- With a childlike appearance but a mature and independent mind
- Sentimental and sensitive
- The “teddy bear” her brother hugs every night in sleep
- Dream: Be able to take care of her parents and herself after all the hardship her mother has endured



Jay Shum

- 18-year-old
- MPS II patient
- Just completed HKCEE, quite aware of the achievement
- Self-described passive person who has not decided what to do in the future
- Always travel around with family; Photography lover
- Dream: Learn to drive and travel to Hokkaido again



Clement Yick, born in Hong Kong in 1964, graduated from Hong Kong Polytechnic Swire School of Design in 1986. He was the Artwork Artist of Kan & Lau Design Associates and promoted to Art Director. Later on, he furthered his career at Lloyd Northover Citigate. In 1996, he started his partnership design business and later on his own graphic design company—Circle Design Ltd. He is dedicated to applying his expertise in providing creative solution in different aspects, including corporate and brand identity, packaging, annual report and other marketing collaterals. His works have received numerous local and overseas awards. He is now the Full Member of Hong Kong Designers Association and actively contributing to the design industry in Hong Kong.

I’m the “**Big D**”

Little Giants’ Great Letters

Ordinary people. Is every person born to be ordinary, or “extraordinary”?

Time flies, I’m now already a 14-year-old teenager. Although people say I look like a 3-year-old little girl, it cannot be denied that I’m a teenager. “Appearance can be deceiving,” many said. I am an “extraordinary” person, who has MPS. My name is Chau Hiu-yin. I hope everyone could be friendly to me. I am no freak, no midget, but just a girl with excessive mucopolysaccharides accumulated in her body cells and organs. Without the right enzymes to decompose them, my body is damaged progressively. I was once a pretty girl with silky hair and a straight back, an energetic child who was able to walk, run and move freely. But now, I’m a barely three-feet-tall chronic patient with abnormally shaped bones, curved fingers and spine, and rough hair. I rely entirely on my family because I cannot walk or stand. If I were not an MPS patient, I would be as tall as my mother now; I would now have big dreams or high aspirations; I could help my mother with the backbreaking housework; I could take my brother everywhere. But those are just my imagination stuck in my heart. If I could have a wish granted now, I wish I could become a normal 14-year-old girl immediately and do whatever I want. (Like go shopping, playing badminton, gateball, table tennis, etc...) But dreams are just dreams, which couldn’t turn into reality. I shall wake up sometime.

I am an optimistic person. If having the disease is my destiny, it happens for a reason. Accepting the reality is all I can do. I shall smile more and live happily every day. “Everyday is a new day,” why bother being unhappy? Every day is like a gift to me. I decided to do my favourite things and cherish every second of my life. As I am no planner, unsatisfactory academic results do not really upset me.

Ever since I can remember, I have had several surgeries. I remembered the pain, the tough days, and how my mother busied and cried for me. As time goes by, those memories start to fade. I wish I wouldn’t have such painful experience for the rest of my life.

In the past, when I was walking in the street or sitting in a baby stroller pushed by my mother, the pedestrians stared at me as if I were a monster. Since we formed the Hong Kong Mucopolysaccharidoses & Rare Genetic Diseases Mutual Aid Group (HKMPS), the community knows much more about us. I feel that more people are caring about us, protecting us and even helping us. I’m no longer alone and desperate. There is always hope for us. MPS, I’m not afraid of you. I’ll survive all the tough times. One day, modern technology will beat you. The Hospital Authority will beat you. And soon, all of us, the Little Giants, will win the long war against you. We’re waiting for our victory.

Now, I’m really grateful for my parents’ effort and perseverance. I am thankful for what HKMPS has done for us. I hope medicines will come to us and there would be a miracle in the healthcare industry.

MPS IV Patient
Chau Hiu-yin
16th March 2008

Little Giants’ Great Letters

My name is Jay Shum, an 18-year-old student who studies arts and business at NSSI Peace Evangelical Secondary School. I’m currently preparing for the HKCEE. I still walk, run, sleep, eat, play... as freely as I can. Among the patients with rare genetic diseases, I think I’m the lucky one. Like many other people, I have a lot of interests—playing computer games, surfing the Internet, travelling around, taking photos, communicating via MSN, hanging out with friends. I chase after several things and of course—my dreams. I wish I could travel to Japan again, learn to drive, work at an office in the future, etc....What makes me different from others is that the disease restricts my movement. My family and I cannot afford the expensive medicine, but if I were given the chance to take it, I would do all the things I haven’t tried before. But well, I would just let it be.

I once read a book that said: “I have never experienced receiving an award on stage. But I believe if I am nominated, I would definitely prepare a thank you speech. As though this is my one and only chance to mention all people I’d like to thank all along, including those irrelevant to the prize.” I agree with such saying. This could be my last chance to thank the people who have been helping me, so I shall use this opportunity.

During PE lessons at school, I couldn’t manage some sports, so I would just stand still and look at the others. But I was still willing to try, hoping one day I’d keep up with them. In these 5 years, I participated in several external competitions. During the second and third years of my secondary study, I attended the Speech Festival (English Solo Verse Speaking). Being a participant for the very first time, I thought I would win. But the result was totally out of my expectation. The winners turned out to be some of my schoolmates, but not me. We were all trained by a teacher who we didn’t know very well at first but later became well acquainted with. He guided us to perform well in the competition. When we came back to school, a deputy class teacher of a F.1 class treated us to McDonald’s, which was remarkable. Although the teachers have already left the school, I still have to thank them for their teaching and enjoyable lessons.

I was a prefect at school for 3 years. Some people may find the duties annoying and bothersome, but I never felt that. I enjoy being a prefect (perhaps it’s because I like managing people). I made an all-out effort to perform any duties. Some students didn’t listen to my advice and they made fun of me. I’d just forget about it. I’m not afraid of them. I’d like to thank Mr. Choy, who encouraged me a lot, especially during the prefect camp.

I’d also like to thank my family – my father, mother and two sisters. They’ve been helping and supporting me all the way. When I was a toddler, my cousin noticed my abnormal fingers. My mother then took me to

queue at an outpatient clinic in Tsuen Wan to see the doctor. I was later referred to Princess Margaret Hospital for a full body check-up and was diagnosed with MPS II. I want to thank my family members with all my heart for their meticulous care over the past 10 years or so. In recent years, I frequently have middle ear infection since I wear a hearing aid. I always have to go to the doctor. It upsets me that the medical bill is very expensive, which is definitely an onerous burden to my family.

Last but not least, I’m grateful to the teachers and schoolmates who have been helping me. I have had a great time at school. It has been a great pleasure studying with you all. I’m touched by all your tender care. I’d like to give special thanks to my class teachers and teachers who have taught me. Thank you very much! Another special thanks to my schoolmates and friends: Julian, Bodey, Lisa, Kammy, and others... You have filled my life with colours and made my secondary school life remarkable—hanging out together, spending Christmas together, etc. THANKS to my FDS! We will rock the exam! To all the kind people who have helped me, I will remember you FOREVER...

Jay
March 2008



Big D’s Replies

Hiu-yin
A vast green grass field is what you enjoy.
Live a full life every day.
Go with the flow
Like the little grass after a storm.
Grow a green grass field on your own
Inside your heart, you walk freely.

Clement

Jay
Care from family members
Love and support from teachers, schoolmates and friends
Together make the happiest moments.
Under your sky
You’re not alone.
Sunny, rainy or cloudy day
We’re all beside you.

Clement



Little Giant the Big Ds Exhibit

The exhibit is a combination of Hui-yin's drawings and Clement's photographic work. Hui-yin loves vast grassy fields, while Jay blue skies. Let's be surrounded by boxes of their dreams and show our love and support. Get closer. Open the boxes. You'll see their little dreams.

Jay Shum X Clement Yick



Chau Hiu-yin X Clement Yick



We Are the **LITTLE GIANTS**

Eric Ma

- 15-year-old
- MPS VI patient
- Secondary school student who receives general education and once came 2nd in his form
- Optimistic person who loves his younger sister
- Always says "I don't mind" as he is satisfied with what he has
- Dream: Get richer than Li Ka-shing; Play football better than Ronaldinho; Stay alive after every sleep



I'm the **"Big D"**



John Lee

- 15-year-old
- MPS IV patient
- Raised by single mother
- Student of Hong Kong Red Cross John F. Kennedy Centre
- Have to use a wheelchair to ambulate
- Talkative person like many other teenagers, except when his mother is beside him
- Dream: Become Superman to fight for justice and protect his mother



Ducky Tse was a journalist and professional photographer for more than a decade. He is now a freelance artist. He devotes himself to recording the urban transitions of Hong Kong and "people-urban space" relation, for example the Queen's Pier Series. He also spent more than 10 years working on one theme, like the West Kowloon Reclamation Project and Hong Kong Political Landscape Series. Recently, Ducky is making statues for factory workers in Mainland China. He was awarded many times by the Hong Kong Press Photographers Association. Ducky has held a number of exhibitions in Hong Kong and overseas and published numerous albums. Some of his work are even collected by the Hong Kong Heritage Museum.

Little Giants' Great Letters

MPS brings me inconvenience, sorrow and setbacks, but it also gives to an unusual experience. For example, frequent follow-up appointments and interviews teach me to treasure my life. My biggest wish is to receive medication and improve my health. I also hope I could get into university and become a contributing person. I wish I could travel more to broaden my horizon. I wish to become a philosopher and a wise person. My idols are Socrates, Plato and Einstein. I hope I'll be able to see my sister get married and have children.

Eric Ma



李尚文：《醃豆豆的心聲vs官員的回應》



Calm down, everybody.
When could we have the medication?
Isn't it already too late after your discussion with other officials?
Thank you, Chief Executive!
Mr. Tsang, when will you approve the financial aid to MPS patients? The medicine costs a million dollars or more every year.
Well, I'm giving order to the Hospital Authority. Its entire surplus goes to the MPS group.
I will ask the Financial Secretary to mention this in the next Budget.
But the medication is expensive. I've to discuss with other officials.

John Lee: Little Giant's voice vs Official's response

Big D's Reply

I gave John a selfie remote and put the camera on a tripod so he could compose the photo and take photos for himself. He had to look at the remote to search for the little red button and press it. Such little movement is no easy task for an MPS patient. John is very optimistic and kind. He likes joking with me. I asked if he had ever thought of committing suicide because of the disease. "Never, there's always a way. What I have to do is to live on," he said. He loves the cartoon Gundam. While I'm still in the era of UC0083, a Gundam series back in the 90s, John is already watching the latest series Gundam Seed Destiny. He has his own Gundam philosophy—"Fight until the end".

By taking selfies, John could see his body, face and other unseen parts. These parts are probably "connected" with him, but have we ever said "hello" to them? Eyes, ears, soles, scars after surgeries... The mirrors in the exhibit enable us to review ourselves. John received Catholic baptism when he was little so I built a small church with tiny red crosses. He isn't much influenced by religion now. He doesn't blame God. I guess he has buried the faith and the Church deep inside his heart.

Without any prior experience in pushing a wheelchair, I took Eric around the city that day. Sitting on a wheelchair, he carefully snapped the skyscrapers along the street. Like many other boys, he is interested in machineries, cars and buildings. To Eric, this city might always be so huge. It requires ridiculous physical strength to run though the whole city. The pictures taken by this young man show his curiosity about the world he lives in. He is curious about little bugs, ignorant cows... As he has difficulty in walking, the enormous size of a cow scared him. He carefully kept a distance from the cow. Like normal people, MPS patients have feelings—fear, joy, and sadness. They wish to be cared for and loved.

Ducky

Little Giant \times the Big Ds Exhibit

#1. Room series No.102

size 300mm W x 900mm H x 300mm L

#2. Room series No.103

size 300mm W x 300mm H x 900mm L

Tiny red crosses carved with the acronym “MPS” are like patients. They’re competing against time and proclaiming their faith, hand in hand. Looking through the boxes which symbolise life, we see joy, misfortune, and of course, the trace of life.

Nowadays, there are medicines to relieve the symptoms and extend MPS patients’ lives. Sponsoring their medication would not place a heavy burden on the government’s healthcare expenditure because they are few in number. Why can’t we give them a happy and comfortable life?

This project is to let more people know about MPS patients, who are a part of our society. They are kind-hearted, struggling for breath in this utilitarian city.



Eric Ma \times Ducky Tse Chi Tak
John Lee







We Are the **LITTLE GIANTS**

Lee Sum-yu

- Almost 4 years old
- MPS I patient
- Caring but playful person
- Received bone marrow transplant about a year ago; couldn't go out since then
- As described by her mother, she was like a bird regaining freedom and curious about anything
- Dream: Go outside; Become a firefighter



Mak Chi-yan

- 10-year-old
- MPS IV patient
- Form 5 student
- Enjoy playing chess, especially Go, and football
- Dream: Become a scientist

I'm the “Big D”



Gideon Lai graduated from the Hong Kong Polytechnic in Graphic Design & Illustration with excellent performance. He is the founder of Ameba Design Ltd. Over the years, he has received more than 100 awards, including Platinum Prize, Gold Awards, Silver Awards, Bronze Awards, Judges Awards, Best Design Awards... etc.

His work “Harmony” won the International Posters’ Solon (France) and was exhibited around the world.

Gideon devotes himself in promoting cultural art designs. His works were exhibited in places like Berlin (Germany), France, Italy, USA, Japan, Korea, Taiwan, China and Hong Kong. Some of his works are collected by museums in Beijing, Hong Kong, Macau and Italy, etc.



Little Giants' Great Letters

I know I have MPS. Every year, I go to Prince of Wales Hospital for follow-up appointments. They check my eyes, bones, heart and metabolism.

I'm easily tired and cannot walk very far. I'm shorter than normal people. My height brings inconvenience during PE lessons.

I wish my condition wouldn't affect my study.

Please care more about MPS patients.

Chi-yan
March 2008

My daughter, Sum-yu, was diagnosed with MPS when she ran a fever 20 months ago. I can't describe our feeling at that moment in words. She totally looked like a normal kid—energetic and adorable, but with curved fingers. After a year of frequent visits to the hospital, we at last arranged bone marrow transplant for her. The surgery was a year ago. It was quite a success. But her bones or some other parts may not recover.

Her brother loves her. Her favourite is her Dad. Sometimes, she asks me, "Mama, are you tired? I'll help you cook when I grow up." She is so sensible and caring.

She hopes she could go to a park or a school. I wish to tell her, "Honey, Mama loves you. If I could, I would bear all your pain and suffering for you. I hope you would understand your condition when you grow up. Don't care about what others say. Just live happily. Mama will always be beside you.

I would like to say "thank you" to the doctors and nurses who have helped my daughter. Thank you for your hard work. May I express the sincerest gratitude to all of you.

Sum-yu's Mom

Dear Chi-yan,

Although we can only talk to each other over telephone and letters, I can feel that you're an adorable and sensible young man. I know you enjoy learning and thinking and you dream to be a scientist.

Trust me. If you're willing to work hard, you would be successful and your life would be meaningful.

Imagine if one day, a small head of broccoli turned into a tall tree, which provides shelter to others and contributes to society, making the impossible possible.

You can also have such exceptional vitality!

Gideon

Big D's Replies

Dear Sum-yu,

Do you know?

When I first met you, you gave me an impression in just 10 minute that you're energetic, lovely, cheerful, pretty and innocent. You're just like a normal girl.

I realised that suffering from the disease at such a young age must be difficult and annoying. But I believe that after all the trials and hardships you've been through, you will become much stronger.

I wish you an energetic and happy life. Like a small broccoli, you'll grow up with joy and beauty.

Gideon

Little Giant ✕ the Big Ds Exhibit

Broccoli has great vitality although it is a small plant. With tender and constant care, it can grow strong and sturdy. It even has limitless potential to contribute to society in the future.

A tiny thing can possess endless possibilities despite its size.



Mak Chi-yan

Lee Sum-yu

Gideon Lai

西二花之树

10 麥智欣
初中級班 第一組

我想成為科學家

小孩子卻有無比生命力量
也可以茁壯成長，豐盛結果
雖然有驚險的人，
微小生命卻能延續生命盡可能！

3½ 李芯瑜
初中級班 第一組

我希望可以快樂地成長



We Are the
LITTLE GIANTS



Annie Yeung (left) – Johnny’s younger sister

- 13-year-old
- MPS VI patient
- Was born in Guangzhou and received education there; Moved to Hong Kong in 2003
- Three years ago, received bone marrow donated by her father to provide enzymes her body lacked
- Loves to smile and draw
- Learnt to play the harmonica from her older brother; Can play “Mary Had a Little Lamb”
- Dream: Become a painter; Receive medication as soon as possible

Johnny Yeung (right) – Annie’s older brother

- 16-year-old
- MPS VI patient
- Was born in Guangzhou and received education there; Moved to Hong Kong in 2003
- Can speak fluent Putonghua and Cantonese; The 2nd runner-up of Hong Kong Putonghua Speech Contest
- Became blind at the age of 11 due to the disease; Have to use a wheelchair to ambulate
- When playing “Twinkle, Twinkle, Little Star” on his harmonica, he would think of his mother and sister
- Dream: Be able to see the stars in the sky; No discrimination

I’m the “**Big D**”



Shana Cheung graduated from the School of Design, Hong Kong Polytechnic University in 2004. She was awarded the Bachelor’s degree in Graphic Design.

In 2004, she published a book based on the true story of blind Kenyan marathon runner, Henry Wanyoike. The book was translated into English, Japanese, German and Braille, and published in various countries.

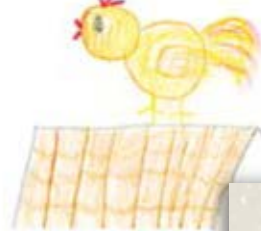
Other works include:

The Invisible Angels which shows you the world of visually impaired children; musical adventure Tommy’s Wonderland (illustration); and Little Giants, Dreams of Braving MPS, which tells you the stories of MPS patients and their families.

Shana believes it is short stories that touch people’s heart.



我希望我的人生好像彩虹一樣美麗。



Annie
17-3-2008



17th March 2008

I hope my life is as colourful as a rainbow.

Little Giants' Great Letters

17th March 2008

I wish I could have better health and all members of the Group would stay healthy. As I can't see, I face great difficulties in my study and daily life. But I won't give up. I will even live a happier life.

Johnny

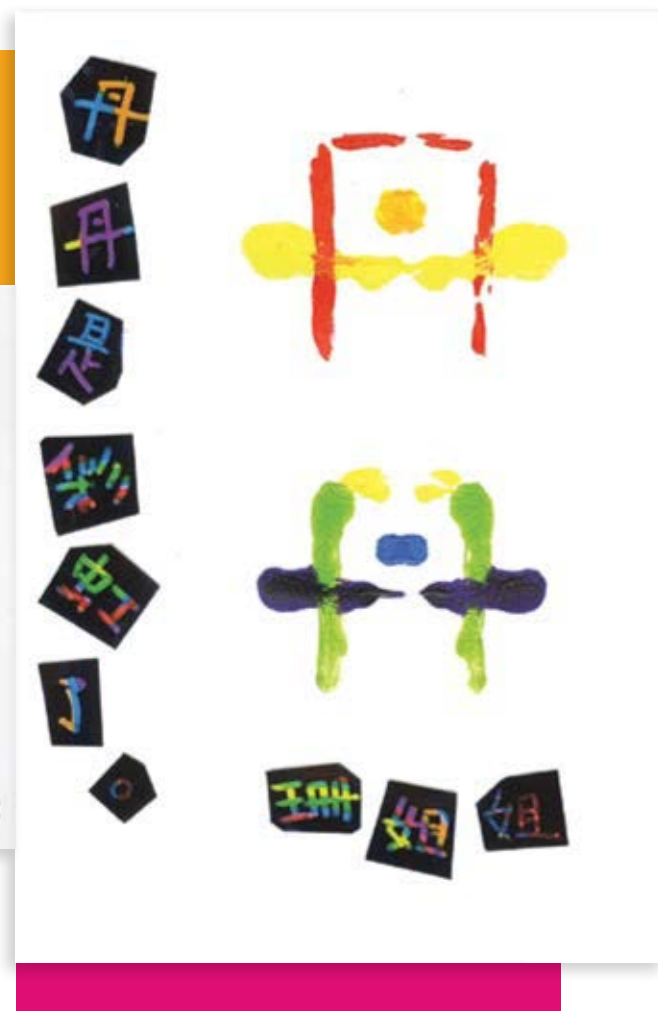
Big D's Replies



Dear Johnny,
Though you can't see, little stars are already beside you. Let me be a star of yours. Together we will shine brightly. Above is a picture I drew. It is my first attempt to create an artwork with Braille. The dots form an image of a truck. It carries a big star, delivering it as a present to your house.

Supporting you always,
Shana

Dear Annie,
Annie is already a rainbow!
Shana





Annie Yeung X Shana Cheung

Little Giant X the Big Ds Exhibit

Annie loves rainbows. She says she wants to be as beautiful as a rainbow. What if everything becomes rainbow-like? Rainbow-like girl, rainbow-like octopus, rainbow-like watermelon...



Johnny Yeung X Shana Cheung

Little Giant X the Big Ds Exhibit

Little Star

Johnny lives in the dark, but he loves to play "Twinkle, Twinkle, Little Star".



Doctor's Words

Treatment Trends in Mucopolysaccharidoses (MPS)

Mucopolysaccharides consist of a series of sugar-like biochemical substances. They can be found in our organs, tissues and bones. MPS is a rare genetic disease. Patients lack a specific kind of enzyme in their body, resulting in the accumulation of mucopolysaccharides in cells and further malfunction of body tissues. The symptoms are not apparent at birth but become more visible as patients grow up. The accumulated mucopolysaccharides cause damage to cells progressively and various body parts, including heart, bones, joints, respiratory system and central nervous system.

MPS is divided into 7 types according to the degree of severity, which varies with the amount of the deficient enzyme. Clinical features include distinct facial features, abnormal bone and cartilage shape, which leads to short body trunk and physical disability, cloudy corneas, and intellectual disability.

Currently there is no cure for MPS. However, better treatment could be provided if it is diagnosed early. In early stages, bone marrow transplant or umbilical cord blood transplantation can improve MPS I and VI patients' condition. According to recent studies, Enzyme Replacement Therapy is proven useful in treating MPS I, II and VI. However, it is very expensive. Patients are also required to receive regular intravenous injections for the rest of their lives. A big challenge is how to put the related enzymes into patients' bones and central nervous system so that all MPS patients, including those with damaged bones and central nervous system, can benefit from the ground-breaking therapy. Apart from that, treating MPS patients with gene therapy is a goal of current genetic research.

Dr. Poon Wing Kit, Grace
Consultant, Hong Kong Mucopolysaccharidoses & Rare Genetic Diseases Mutual Aid Group
Paediatrician, Department of Paediatrics & Adolescent Medicine

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12 Little Giants

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Lee Sum-yu & Mak Chi-yan /
Annie Yeung & Johnny Yeung

7 Big Ds

Amanda Fung / Yanki Lee /
Another mountainman (Stanley) / Clement Yick /
Ducky Tse / Gideon Lai / Shana Cheung

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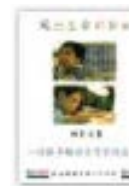
輕舟・重山 一個龐貝氏症患的心路歷程

Author: Joe Lai | Publication Date: April 2012 |
Publisher: Riding Cultural and Creative Limited |
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大不了的3呎高人生—罕有病少年的濃縮人生自白書

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寫出生命的彩虹——一位黏多醣症女作家的自白

Author: 陳雯芳 | Publication Date: 1999 | Publisher: Metro Broadcast Corporation Limited | Language: Traditional Chinese | Pages: 105 |
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Books in Chinese

We are the Little Giants, which actually refers to MPS patients. We were born without a particular enzyme. As excessive mucopolysaccharides are accumulated in our bodies, we have difficulties seeing and hearing. We are vertically challenged and doomed to have a short life. The disease is in fact treatable. But we could not afford the medical bill of nearly a million dollars per year. We have a small body, but distant dreams.

“The Big Ds”—are 7 excellent designers and creators in Hong Kong, including Amanda Fung, Another mountainman (Stanley), Clement Yick, Ducky Tse, Gideon Lai, Shana Cheung and Yanki Lee. By keeping correspondence with 12 Little Giants, they feel their dreams in the heartfelt conversation and process of creating exhibits.

The exhibition **“Little Giants X the Big Ds”** displayed 12 artworks created by 12 Little Giants and 7 “Big Ds” to say their dreams out loud.

This book **“Little Giant · Great Letters”** records the interaction and conversation among Little Giants and Big Ds with texts and pictures. It was published to raise funds for Hong Kong MPS & Rare Genetic Diseases Mutual Aid Group. We hope to spread the message: a weak body does not necessarily obstruct one’s firm approach to dream.

“These stories aren’t like those about a million of poor people on TV. They’re about what we might have overlooked, and what we don’t know but want to know.”

– **Claudia Mo, Veteran Journalist**

“Recently, our government tends to use the concept of cost-effectiveness to respond to opinions about healthcare. But life is priceless. How could we possibly let those kids with MPS see themselves getting worse everyday, but not give a helping hand?”

– **Fernando Cheung, member of the Legislative Council**

“There are only about 30 MPS patients in Hong Kong. The disease is rare in other places as well so the medication is highly priced. Yet, our government is not giving a full sponsorship to the patients. As a doctor, I cannot accept that they are not receiving a suitable treatment due to financial limitation. So I decided to support them.”

– **Dr. Ko Wing-man, Chairman of Hong Kong Anti-Cancer Society**

Please
affix stamp

Dr. York Chow
Secretary for Food and Health, HKSAR Government

19th floor, Murray Building,
Garden Road, Hong Kong

Secretary for Food and Health, HKSAR Government
19th floor, Murray Building,
Garden Road, Hong Kong

Dear Dr. Chow,

I believe you know there is a small group of Mucopolysaccharidoses (MPS) patients in Hong Kong. Because of the rare genetic disease, these patients have rough faces, twisted arms and legs and a small body. More critically, their vital organs—hearts, livers and eyes—will gradually fail because of the disease. Most of them do not live to 20 years old.

Although there are drugs to treat these patients, the cost of treatment runs up to more than a million dollars per year; and the vast majority of patients cannot afford it. To the families, they can only watch helplessly as their children's bodies deteriorate, until their brief lives end.

MPS patients' bodies are fragile, their lives are short, and yet they know how to love a tough life better than the ordinary people. Their resilience deserves our respect. Society and the government should also respond to the patients' basic want of survival positively.

Unfortunately, despite our government's strong financial strength, "cost effectiveness" remains a criterion when considering whether to provide medical treatment to the patients. Because of that, Hong Kong's 30 or so MPS patients who cannot receive funding can do nothing but await death.

I believe the government should immediately abandon the "cost effectiveness" thinking because every life is precious. The value of life should not be measured by cost or effectiveness.

I am therefore sending this letter in support of the MPS patients. I hope you can accept the basic wish for survival by this small group of MPS patients, for every life deserves respect.

Signature: _____

Full Name: _____

Date: _____